

General

Title

Advanced cancer outpatient experiences: overall satisfaction score on the 13-item FAMCARE-Patient scale.

Source(s)

University Health Network. FAMCARE P13. Toronto (ON): University Health Network; 2009. 1 p.

Measure Domain

Primary Measure Domain

Clinical Quality Measures: Patient Experience

Secondary Measure Domain

Does not apply to this measure

Brief Abstract

Description

This measure is used to assess the overall satisfaction score on the 13-item FAMCARE-Patient scale (FAMCARE-P13).

Patients with advanced stage cancer rate their satisfaction with outpatient palliative care interventions. An overall satisfaction score is calculated based on the patients' responses ("1 - Very dissatisfied," "2 - Dissatisfied," "3 - Undecided," "4 - Satisfied," "5 - Very satisfied") to the following items:

How satisfied are you with:

- How thoroughly the doctor assesses your symptoms
- Information given about how to manage pain
- The availability of nurses to answer your questions
- Information provided about your prognosis
- Speed with which symptoms are treated
- Information given about your tests
- The way tests and treatments are performed

The availability of doctors to answer your questions
Answers from health professionals
Referrals to specialists
The way tests and treatments are followed up by the doctor
Information given about side effects
The way the family is included in treatment and care decisions

A prorated FAMCARE-P13 score is calculated if at least 6 items are completed. Scores range up to 65, with higher scores indicating higher levels of satisfaction with care.

Rationale

Effectiveness of oncology care has traditionally been measured in terms of biomedical outcomes, such as survival and disease-free survival. However, the importance of patient and family-reported outcomes for clinical trials in oncology is increasingly acknowledged, and such outcomes are increasingly incorporated into cancer clinical trials (Lipscomb et al., 2007; Garcia et al., 2007). Subjective outcomes are particularly important in the palliative setting, where the focus is explicitly on quality of life for the patient and family (World Health Organization [WHO], 2009).

In studies assessing the effectiveness of palliative care interventions, relevant patient outcomes include symptom control, quality of life, quality of death and satisfaction with care (Bruera et al., 1991; Dy et al., 2008; Zimmermann et al., 2008; Hales, Zimmermann, & Rodin, 2008). The most consistent improvement has been shown for satisfaction with care (Zimmerman et al., 2008), which is a distinct concept encompassing symptom management, emotional support, communication, accessibility and coordination of care, and support of patients' decision-making (Dy et al., 2008). However, a hindrance in the assessment of satisfaction with palliative cancer care has been the lack of measures that are validated specifically for patients with advanced cancer (Mularski et al., 2007).

Evidence for Rationale

Bruera E, Kuehn N, Miller MJ, Selmsler P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care*. 1991 Summer;7(2):6-9. [PubMed](#)

Dy SM, Shugarman LR, Lorenz KA, Mularski RA, Lynn J, RAND-Southern California Evidence-Based Practice Center. A systematic review of satisfaction with care at the end of life. *J Am Geriatr Soc*. 2008 Jan;56(1):124-9. [41 references] [PubMed](#)

Garcia SF, Cella D, Clauser SB, Flynn KE, Lad T, Lai JS, Reeve BB, Smith AW, Stone AA, Weinfurt K. Standardizing patient-reported outcomes assessment in cancer clinical trials: a patient-reported outcomes measurement information system initiative. *J Clin Oncol*. 2007 Nov 10;25(32):5106-12. [PubMed](#)

Hales S, Zimmermann C, Rodin G. The quality of dying and death. *Arch Intern Med*. 2008 May 12;168(9):912-8. [PubMed](#)

Lipscomb J, Reeve BB, Clauser SB, Abrams JS, Bruner DW, Burke LB, Denicoff AM, Ganz PA, Gondek K, Minasian LM, O'Mara AM, Revicki DA, Rock EP, Rowland JH, Sgambati M, Trimble EL. Patient-reported outcomes assessment in cancer trials: taking stock, moving forward. *J Clin Oncol*. 2007 Nov 10;25(32):5133-40. [PubMed](#)

Lo C, Burman D, Hales S, Swami N, Rodin G, Zimmermann C. The FAMCARE-Patient scale: measuring satisfaction with care of outpatients with advanced cancer. *Eur J Cancer*. 2009 Dec;45(18):3182-8. [40 references] [PubMed](#)

Mularski RA, Dy SM, Shugarman LR, Wilkinson AM, Lynn J, Shekelle PG, Morton SC, Sun VC, Hughes RG, Hilton LK, Maglione M, Rhodes SL, Rolon C, Lorenz KA. A systematic review of measures of end-of-life care and its outcomes. *Health Serv Res.* 2007 Oct;42(5):1848-70. [PubMed](#)

World Health Organization (WHO). WHO definition of palliative care. [internet]. Geneva (Switzerland): World Health Organization (WHO); 2009 [accessed 2009 Mar 06].

Zimmermann C, Riechelmann R, Krzyzanowska M, Rodin G, Tannock I. Effectiveness of specialized palliative care: a systematic review. *JAMA.* 2008 Apr 9;299(14):1698-709. [PubMed](#)

Primary Health Components

Advanced cancer; palliative care; patient satisfaction

Denominator Description

Total number of items answered on the 13-item FAMCARE-Patient scale (FAMCARE-P13) by outpatients with advanced cancer, 18 years of age and older, with a prognosis of 6 months to 2 years who completed at least 6 items on the FAMCARE-P13 (see the related "Denominator Inclusions/Exclusions" field)

Numerator Description

Sum of the item responses multiplied by 13 (see the related "Numerator Inclusions/Exclusions" field)

Evidence Supporting the Measure

Type of Evidence Supporting the Criterion of Quality for the Measure

A systematic review of the clinical research literature (e.g., Cochrane Review)

One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

Additional Information Supporting Need for the Measure

Unspecified

Extent of Measure Testing

Methods. The authors analysed data from 315 outpatients with advanced cancer participating in a randomised controlled trial of early palliative care intervention versus routine oncology care, and their caregivers. Patients completed a 16-item measure of patient satisfaction (FAMCARE-P16), based on the FAMCARE measure of family satisfaction with cancer care, and measures assessing interactions with healthcare providers, performance status and symptom burden. Caregivers completed the original FAMCARE measure. The authors used confirmatory factor analysis to test the patient satisfaction measure for a single-factor structure. To determine construct validity, they assessed correlations between patient satisfaction and the other patient and caregiver measures. To assess responsiveness to change, they repeated paired t-test analyses on the 13-item and 16-item scales for 150 patients participating in a

phase II trial of palliative care effectiveness, in which the FAMCARE-P was measured at baseline, 1-week and 1-month after an outpatient palliative care intervention.

Results. A reduced 13-item version of their measure (FAMCARE-P13) possessed a one-factor structure with high reliability. Patient satisfaction was correlated in predicted directions with physical distress, communication and relationship with healthcare providers, and caregiver satisfaction. There were statistically significant increases in patient satisfaction at 1 week (p less than 0.0001) and 1 month (p less than 0.001).

Refer to *The FAMCARE-Patient Scale: Measuring Satisfaction with Care of Outpatients with Advanced Cancer* for more information.

Evidence for Extent of Measure Testing

Lo C, Burman D, Hales S, Swami N, Rodin G, Zimmermann C. The FAMCARE-Patient scale: measuring satisfaction with care of outpatients with advanced cancer. *Eur J Cancer*. 2009 Dec;45(18):3182-8. [40 references] [PubMed](#)

State of Use of the Measure

State of Use

Current routine use

Current Use

not defined yet

Application of the Measure in its Current Use

Measurement Setting

Ambulatory/Office-based Care

Hospices

Hospital Outpatient

Professionals Involved in Delivery of Health Services

not defined yet

Least Aggregated Level of Services Delivery Addressed

Clinical Practice or Public Health Sites

Statement of Acceptable Minimum Sample Size

Unspecified

Target Population Age

Age greater than or equal to 18 years

Target Population Gender

Either male or female

National Strategy for Quality Improvement in Health Care

National Quality Strategy Aim

Better Care

National Quality Strategy Priority

Person- and Family-centered Care

Institute of Medicine (IOM) National Health Care Quality Report Categories

IOM Care Need

End of Life Care

Living with Illness

IOM Domain

Patient-centeredness

Data Collection for the Measure

Case Finding Period

Unspecified

Denominator Sampling Frame

Patients associated with provider

Denominator (Index) Event or Characteristic

Clinical Condition

Patient/Individual (Consumer) Characteristic

Denominator Time Window

not defined yet

Denominator Inclusions/Exclusions

Inclusions

Total number of items answered on the 13-item FAMCARE-Patient scale (FAMCARE-P13) by outpatients with advanced cancer, 18 years of age and older, with a prognosis of 6 months to 2 years who completed at least 6 items on the FAMCARE-P13

Exclusions

Unspecified

Exclusions/Exceptions

not defined yet

Numerator Inclusions/Exclusions

Inclusions

Sum of the item responses multiplied by 13

Note: Prorated FAMCARE-P13 score = $[(\text{sum of individual items}) * 13] / \text{total number of items answered}$. Score if at least 6 items are completed. Scores range up to 65, with higher scores indicating higher levels of satisfaction with care.

Exclusions

Unspecified

Numerator Search Strategy

Fixed time period or point in time

Data Source

Patient/Individual survey

Type of Health State

Does not apply to this measure

Instruments Used and/or Associated with the Measure

13-Item FAMCARE-Patient scale (FAMCARE-P13)

Computation of the Measure

Measure Specifies Disaggregation

Measure: Species Disaggregation

Does not apply to this measure

Scoring

Composite/Scale

Mean/Median

Interpretation of Score

Desired value is a higher score

Allowance for Patient or Population Factors

not defined yet

Standard of Comparison

not defined yet

Identifying Information

Original Title

FAMCARE P13.

Submitter

University Health Network - Academic Affiliated Research Institute

Developer

University Health Network - Academic Affiliated Research Institute

Funding Source(s)

Canadian Cancer Society

Composition of the Group that Developed the Measure

- Dr. Camilla Zimmermann
- Dr. Christopher Lo
- Debika Burman
- Nadia Swami

Financial Disclosures/Other Potential Conflicts of Interest

None to declare

Adaptation

This measure was adapted from the original 20 item FAMCARE meant for family caregivers:

Kristjanson LJ. Validity and reliability testing of the FAMCARE Scale: measuring family satisfaction with advanced cancer care. Social Science and Medicine 1993;36(5):693-701.

Date of Most Current Version in NQMC

2009 Jan

Measure Maintenance

No regular schedule

Date of Next Anticipated Revision

Unspecified

Measure Status

This is the current release of the measure.

Measure Availability

Source not available electronically.

For more information, contact the University Health Network at the Princess Margaret Cancer Centre, 610 University Ave, Toronto, ON, Canada, M5G 2M9; Phone: (416) 946-4545; Email: camilla.zimmermann@uhn.ca; Web site: www.uhn.ca .

NQMC Status

This NQMC summary was completed by ECRI Institute on September 28, 2016. The information was verified by the measure developer on October 18, 2016.

Copyright Statement

No copyright restrictions apply.

Production

Source(s)

University Health Network. FAMCARE P13. Toronto (ON): University Health Network; 2009. 1 p.

Disclaimer

NQMC Disclaimer

The National Quality Measures Clearinghouse (NQMC) does not develop, produce, approve, or endorse the measures represented on this site.

All measures summarized by NQMC and hosted on our site are produced under the auspices of medical specialty societies, relevant professional associations, public and private organizations, other government agencies, health care organizations or plans, individuals, and similar entities.

Measures represented on the NQMC Web site are submitted by measure developers, and are screened solely to determine that they meet the [NQMC Inclusion Criteria](#).

NQMC, AHRQ, and its contractor ECRI Institute make no warranties concerning the content or its reliability and/or validity of the quality measures and related materials represented on this site. Moreover, the views and opinions of developers or authors of measures represented on this site do not necessarily state or reflect those of NQMC, AHRQ, or its contractor, ECRI Institute, and inclusion or hosting of measures in NQMC may not be used for advertising or commercial endorsement purposes.

Readers with questions regarding measure content are directed to contact the measure developer.